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# From the Theoretical to the Personal: Weighing Further Feminist Concerns on Physician-Assisted Suicide and Euthanasia

Norah Martin

*University of Portland*, [martinn@up.edu](mailto:martinn@up.edu)

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**From the Theoretical to the Personal: Weighing Further Feminist Concerns on Physician-Assisted Suicide and Euthanasia**

**Norah Martin  
University of Portland**

In 2003 I published a paper entitled “Physician-Assisted Suicide and Euthanasia: Weighing Feminist Concerns.” The paper was a response to Susan Wolf’s “Gender, Feminism, and Death: Physician-Assisted Suicide and Euthanasia” (1996) and to Sydney Callahan’s arguments in “A Feminist Case Against Euthanasia” (1996). They argue that physician-assisted suicide [PAS] is a danger to women because, given women’s traditional role as self-sacrificing, and, given that women are traditionally less valued in society, women are more likely to be pressured to request PAS or simply to have been socialized in such a way as to feel that they should request it to avoid being a burden. Wolf points out that suicide is more often attempted by women, though more often completed by men, suggesting that women’s requests for PAS may, more often than men’s, be an effort to change an oppressive situation rather than a literal request for death. In addition, Wolf is critical of the rhetoric of rights that surrounds debates about PAS and euthanasia.

While I found that Wolf and Callahan raise important issues, I found their arguments against PAS unconvincing. I raised the concern that “women are generally socialized to be less assertive than men and tend to have less of a sense of entitlement when dealing with mostly male authority systems. [Such] authority systems are most likely to discount

women's voices" (Martin 2003: 139). Callahan (1996) cites a study by Jecker that shows that women's medical treatment preferences "were more often ignored because the courts 'treated prior evidence of women's values and choices as immature, emotional, or uninformed, but considered men's prior statements and lifestyle decisions to be mature and rational'" ([Jecker 1994: 676] Callahan 1996: 23). She concludes "old women will bear the brunt of any inadequacies in the system our society devises for the fragile old at the end of life" (Callahan 1996: 23). I said that while Callahan sees this as a reason to find that PAS will be more likely to be imposed on women, it seemed to me that precisely the opposite conclusion could be drawn from the same data:

The Oregon assisted suicide law requires that one actively request death on several occasions, that one satisfy one's doctor that one is making a rational decision in requesting death, and that one must have the cooperation of more than one doctor. If women's voices are less often heard and their decisions more often considered irrational and emotional, and if they are less assertive in male-dominated authority systems than are men, then it seems likely that women are far less likely to go through the steps of requesting PAS, and if they do, are far less likely to have their requests acted upon. If anything, it seems that women would be unfairly discriminated against in that they would be less likely to be able to take advantage of the laws, like the one in Oregon, allowing PAS" (Martin 2003: 139).

The assisted suicide law in Oregon<sup>1</sup> "assumes the existence of an autonomous, genderless, classless, and contextless decision maker whose rationality must be decided upon before the request for physician assistance can be acceded to" (Martin 2003: 140).

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<sup>1</sup> I wrote about the assisted suicide law in Oregon because at the time Oregon was the only U.S. state in which PAS was legal. Today it is also legal in the states of Washington and Vermont. All three of these laws are very similar, with Washington and Vermont modeling their laws on the Oregon law. Everything I said with reference to the Oregon law in 2003 is true of the Washington and Vermont laws as well.

The Oregon assisted suicide law also “does not make any provision for input from loved ones when a suicide decision is made” (Martin 2003: 140). Would such input be relevant? It would certainly not be from a personal autonomy standpoint. From a relational care perspective it would be relevant, though also problematic given that one could be subject to coercion based on the desires of one’s family.

In August 2012 my mother asked me for a “euthanasia pill.” That was when what had been an issue of theoretical concern became one of personal concern. When I wrote my 2003 paper I had my mother, then healthy in her mid-70’s, in mind. This is a woman who, against social (and family) pressures and expectations of the time, had had a career and lived in a fiercely independent way, despite her desire for children, until she met my father when she was already in her 30’s. My mother then came to define herself around her role as a mother. Self-sacrifice for her children (and, to a lesser degree, others she loved) was part of her self-concept. It seemed to me that she would have a deeply felt desire not to be a burden to those she loved. That desire may have been socially constructed, but it is hard to see how all of our desires are not socially constructed. This does not make them any less real. We might question whether this desire is a bad one, or whether it is one that should be encouraged in men as well. But given certain widely held conceptions of the social construction of the self, it is hard to see how we can argue that such desires are not real for the people that experience them.

I also had my mother in mind because, as Dena Davis has pointed out, “the self-sacrifice [expected of women] is to undergo long periods of pain and disability, perhaps even

dementia, rather than to do something as dramatic and unconventional as to put an end to one's life" (Davis 1998: 119). Indeed, my mother had been unconventional in all sorts of ways in her life. She was someone who thought that making a fuss (or "a scene," as she would put it) is one of the worst things a person could do, so she would not have wanted to do something "dramatic," but doing something unconventional... *that* she would have embraced! Finally, I had my mother in mind because if one were to take advantage of the assisted suicide law in Oregon (or, now, Washington, her state of residence), one would have to make quite a "fuss!"

When my mother made her request, she had recently been diagnosed with a very large acoustic neuroma. The diagnosis came because she had sudden onset extreme confusion, which turned out to be the result of hydrocephalous caused by the tumor. Due to her confusion, she could not participate in any treatment decision. Ultimately, I decided that the best option was for her to have a shunt surgically implanted to drain fluid from her brain. The alternative would have been death, whereas the shunt promised a return to normalcy. My mother was now in her mid-80's. Recovery from the surgery was much more difficult than the doctors anticipated, but two months after her surgery she was achieving the highest scores possible on all of the cognitive tests she was given, and clearly was fully recovered mentally. It was such a relief to have her back! Physically she was also doing remarkably well. She was walking well with a walker, strong enough to do things some of her therapists could not do, and had even been able to go back to swimming laps. She still had 24-hour caregivers, which allowed us to keep her in her independent living apartment in her retirement community throughout her recovery.

However, the tumor meant that it was no longer a good idea for her to drive (something she had been doing, albeit in a limited area, up until the onset of her confusion). She still had a lot of fatigue. She also had significant hearing problems, increasing vision problems, and now her eyes were quite uncomfortable. When we suggested that we could reduce her dependence on caregivers given how well she was doing, she was adamant that she did not feel comfortable doing without them and talked primarily about her vision as the reason. I scheduled her for minor eye surgery that promised to make her eyes more comfortable. It was at this point, when things from my perspective were going quite well, that she asked her caregiver to tell me to bring a “euthanasia pill” when I came over with groceries.

With this request, all of the concerns I raised in my paper were manifest. At least in part because of her hearing loss she had lost confidence in her ability to talk with her doctors, and indeed she had never felt particularly empowered in her dealings with doctors. As a result, I had become her medical representative. Thus there was no way she could make the request of a doctor without my presence and my assistance. In addition, she had recently had significant cognitive impairment and continued to have a brain tumor. It seemed unlikely that she would be considered to be in a rational state when making her request.

When I asked her why she wanted the euthanasia pill, she explained that she was no use to anyone, was a lot of trouble, she couldn’t see, couldn’t hear. This was all consistent with the woman I had long known. She prized independence, now she was dependent on

caregivers and actually afraid to be without them. She was also dependent on me in ways she did not like being dependent. She had always been concerned about me trying to do too much, and now here I was with a job, and my own family, and I was taking care of her. She had trouble reading. She had trouble knitting (she had a record-breaking number of volunteer hours at the hospital from all of the baby sweaters she had knit for babies born into poor families). I could not imagine that she would be able to make this request of anyone but me, and I certainly couldn't make the request on her behalf – that would certainly not have been covered by the law. But I also did not want her to die. It seemed to me that she was doing better and would continue to get stronger and improve. It seemed to me that it was not entirely rational for her to want to end things now. But perhaps that was not my call. When I explained to her that she did not meet the criteria for using Washington's assisted suicide law (for one thing, no doctor would say that she was within 6 months of death), I also told her that there were still people that needed her and to whom she was important. "You are James and my *mother*," I concluded.

"So I'm stuck with it? I just have to live with it?" she responded. I nodded, "yes." She went to take a nap and got up 20 minutes later with a positive attitude and never mentioned this again.

Unfortunately, the doctors were wrong about her prognosis. While acoustic neuromas are usually slow growing tumors, hers was not. Radiosurgery was recommended as the best intervention. I laid out all of the options for my mother. She told me that it was up to me. She'd do whatever I wanted her to do. I tried to get her to make a decision. I said if she

wanted to do nothing, I would support that. She refused to choose, continuing to say that she would do whatever I wanted.

Shortly after her sessions of radiosurgery, she stopped eating almost entirely. She was also drinking very little. Already very thin, she became dangerously thin and weak. No amount of coaxing or encouragement or reasoning with her seemed to make a difference. Was she taking matters into her own hands and suiciding through starvation? I don't know. Certainly many elderly people stop eating at the end. But this was not supposed to be the end. Her doctor prescribed an appetite enhancer. That worked and she gained back the weight she lost, and then some. Should we have given her the appetite enhancer? I don't know.

My mother suffered a lot during her final months. The tumor grew despite the radiosurgery. Her suffering was not from pain from the tumor, but from the various indignities that go with one's body no longer functioning properly. After a hospitalization for an impaction that could have been taken care of at home had we had hospice<sup>2</sup>, I sought out hospice care and changed our approach to palliative care only. I had no idea

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<sup>2</sup> In the U.S., hospice care is normally in-home, with the goal of allowing the patient to die at home. Visiting R.N.'s oversee all care and visit as often as necessary. Family members do the day-to-day care, which sometimes involves being trained to use medical devices by hospice nurses. Due to my mother's privileged financial position, we used professional caregivers from a separate agency, which we paid privately. We had already been using such caregivers and a private pay visiting nurse service to keep my mother out of a nursing home. I performed tasks that licensed home health caregivers are legally prohibited from performing. I was extremely fortunate to be on a long planned for sabbatical leave during the final six months of my mother's life, and to have a job that allows for considerable flexibility when not on sabbatical. This flexibility coupled with my mother's financial resources put us in an incredibly privileged position for dealing with her illness.



whether she was within six months of dying, but I found a doctor who was willing to order hospice care, and keeping Mom out of the emergency room, to which we had been sent far too often, seemed like a good reason to change our approach, even if she subsequently were found not to qualify, as happens for some patients. When I asked my mother if it was okay with her that we get hospice care for her, she said that I had things right. I think perhaps she was just waiting for me to come around to her way of thinking. She died much sooner than anyone thought she would, just a few months after going on hospice care.

I know many people who have lost their parents in recent years. I am that sort of age. A number of them talk about what a great experience it was for them, how they were there for their parents, how the death was beautiful. I was there throughout my mother's illness. I took her to every doctor's appointment. I gave her enemas (licensed home health caregivers in the state of Washington are not allowed to do that; only nurses with a doctor's order [or family members, of course] may legally give an enema), I made all of her medical decisions, and I was there when she died at home after several days of being unconscious. It was not beautiful. It was not a "great experience." It was not for me or about me. It was her experience.

I could have made it better. I still think that it would not have been appropriate to have helped her to die when she asked. At that point, if that was what she really wanted, she already had the means to do so if she thought about what was in her medicine cabinet, and she had the ability to do it when her caregiver was in the bathroom or taking out the

garbage. She also at that point could have gotten her caregiver out of the apartment on a pretext. I am much less certain that I did the right thing in getting her an appetite enhancer when she stopped eating.

Have I changed my position on physician-assisted suicide and euthanasia as a result of these experiences? In my paper, I raised concerns more than I took a position. Those concerns were made more salient by my experience. One of my primary concerns with respect to feminist positions opposing PAS was that “in denying suffering women the ability to choose to die, we fail to respond to their suffering and thus sacrifice caring for them in the name of fighting the oppression of women more general” (Martin 2003: 135). I am not sure if when my mother stopped eating she was deliberately choosing to die. If that is what she was doing, I certainly did not respect that decision when I got her an appetite enhancer. When she asked for a euthanasia pill she was making a request to which I could not legally accede, but also to which I did not want to accede. How much of what I did and did not do was for me and how much was for her, I don’t think I will ever know.

Physician-Assisted Suicide laws such as those in Oregon and Washington are not intended for people like my mother, for frail old women (and men) in their 80’s. They are intended for younger people with greater senses of autonomy and self-efficacy who are willing to make a bit of a fuss — people who are able to look after their own interests even if they are quite disabled. Sandra Bem, who three years after her diagnosis with Alzheimer’s disease, took her life with pentobarbital pills with the support of her family

would not have qualified for PAS. She was not within 6 months of death and the fact of her Alzheimer's disease would call into question her ability to make a rational decision when the time came, even if she had been rational when she collected the pills, presumably several years earlier. I do not know how she got the medication she used to kill herself. I admire her family for supporting her decision. I don't know that I could have done the same.

For those of us who love someone who requests to die, especially those of us who are primary caregivers, we must ask ourselves how sincere the request really is. The law requires that the person ask on more than one occasion. My mother only asked once. I think she may have been looking for my permission, since she had the means to do it if she really wanted to. Was I the worst representation of patriarchy in not giving her permission? I could have done so without using the assisted suicide law – I simply could have pointed out that if she wanted to do it, she had the means in her cabinet and we would not stop her. But I would have stopped her. I did not think she was making a rational decision, even if her reasoning had seemed unimpaired of late. Her desire not to be a burden was consistent with the woman I had always known, but the desire not to cause her children any unnecessary pain was also a significant value for her, and I had to be honest that it would cause James and me a lot of pain. Eventually nature took its course and she died. That was necessary pain for James and me. Earlier would have been unnecessary pain, especially at that particular point when things were looking promising for an eventual return to the way things were before the hydrocephalous. For her, perhaps

seeing that as the best she could hope for was not very motivating. She had told me for a number of years that getting old was “not for wimps.”

I believe that I did ask my mother to make the final sacrifice of suffering through to the end. I don’t think that if she could really have chosen what was to happen, that that’s what she would have chosen. On the other hand, I don’t think she would have chosen for James and me to suffer the pain we suffered in losing her if she could have prevented that pain. Would we have suffered more if her death had come earlier? I think the year of caring for her allowed us to come to terms with the inevitable. So her final sacrifice was made to prepare us as best we could be for her loss. And the law required that sacrifice because she could not qualify for assisted suicide even in Washington, where it was legal. Perhaps she was as conflicted as I am as to what she really wanted, which of her values was the one she wanted to act on.

Perhaps the value of PAS laws is that we must have these conversations and wrestle with our competing desires, hopes, and fears. It seems clear to me that the way these laws are constructed, women and other oppressed groups are at a disadvantage should they wish to avail themselves of the right offered by them. But they do force people like me to wrestle with our obligations in a deeper way than as if the laws did not exist.

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**Norah Martin is an associate professor of philosophy at University of Portland, where she also serves as associate dean in the College of Arts and Sciences. Her publications include articles in the *International Journal for Feminist Approaches to Bioethics* and the *Journal of Medicine and Philosophy*, as well as in several edited collections.**